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ABSTRACT

This report discusses the need to provide people with disabilities with accessible opportunities for community contribution and to provide the individualized supports and assistance necessary to enable their participation. Two strategies are discussed for realizing these objectives: adequate individual funding controlled by people with disabilities and their families and friends; and a process of culture change through community engagement. Two models of the community engagement process are presented that directly involve more people and associations and promote higher levels of organization among people with disabilities and their families and friends. Possibilities for action are described and include: (1) create more family groups; (2) support leadership from among people with disabilities; (3) tell powerful stories; (4) keep person-centered planning vital and outside the orbit of the service system; (5) maintain clear links to political action while pursuing a distinct strategy; (6) develop cooperative projects; and (7) offer formal learning opportunities. (CR)

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COMMUNITY ENGAGEMENT: A NECESSARY CONDITION FOR SELF-DETERMINATION AND INDIVIDUAL FUNDING

by
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1999

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Community Engagement

A Necessary Condition for Self-Determination and Individual Funding

John O'Brien

Contents

The call for change 2
Five trends that shape the strategy 3
Opposition to current policy and advocacy for individualized funding 3
Desire to change faulty assumptions and the backward policies that result 3
Competing understandings of scarcity 4
Knowledge of better ways 6
A deeper understanding of the change process 9
Two models of the community engagement process 11
Organizing relationships 11
Shifting the circuits of culture 13
Possibilities for action 16
Create more family groups 16
Support leadership from among people with disabilities 16
Tell more powerful stories 17
Keep person-centered planning vital outside the orbit of the service system 18
Develop more ways to gather and disseminate information 18
Maintain clear links to political action while pursuing a distinct strategy 19
Develop cooperative projects 19
Offer formal learning opportunities 19

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This paper is based on a meeting of the Community Engagement Working Group held in Pickering, Ontario on 25 March 1999. Family members, service workers, and people with disabilities concerned about building a strong foundation for community living in Ontario make up the working group. I am grateful to members of this group for their insight into the work that must be done to make giving people with disabilities and their families control of adequate individual budgets more than a band-aid solution. This paper reflectts their thinking. Judith Snow, a member of the working group, convened a discussion of an earlier version of this paper at the Toronto Summer Institute on Inclusion and Community in July 1999. Members of this discussion group made editorial suggestions and encouraged wider circulation of a more general form of the original paper.

Preparation of this paper was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B30072) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

The call for change

People with disabilities and their families and friends* have a reasonable expectation that people with disabilities will live with security and dignity as contributing members of their communities. Security, dignity, and contribution depend on people, associations, economic actors, and governments each assuming their fair share of the personal and public responsibility necessary to assure the creation and use of accessible opportunities for contribution and the provision of the individualized support and assistance necessary to enable participation.

Many family members see sobering, even frightening, evidence that this reasonable expectation is not currently shared by their government and by many of their fellow citizens. Policy seems to increase competition among a growing number of people and families for already inadequate and apparently shrinking resources. The number of people waiting for assistance adequate to meet modest needs grows. People remain living at home with parents long past a reasonable time to move out and establish their own households. People slip into nursing homes and institutions for lack of sufficient local resources. Fighting and fighting again and again to get and preserve the funding necessary to provide adequate assistance tires and stresses those people with disabilities and families with the will to seek positive change and discourages others from doing more than passively accepting what is on offer. The number of real allies among service managers, civil servants, and politicians seems to be decreasing as the service system publicly embraces the concepts of choice, individual budgeting, person-centeredness, and accountability for meaningful life outcomes. Concern grows that disabled sons and daughters and brothers and sisters face an environment inhospitable to their living with dignity and security as contributors to the common life.

A hopeful response to this difficult time calls for two distinct but complementary strategies. One strategy guides political action to entrench a policy of adequate individual funding, controlled by people with disabilities and their families and friends. The other guides a long-term process of culture change through community engagement. While these two strategies each make a

* "Friends" includes those paid service workers who act from sustained personal commitment to the well-being of a particular person with a disability and are recognized by that person as a friend. This form of friendship could mask subtle efforts to control people or expose people to the stress of conflicting interests. However, ruling others out of the possibility of friendship on the basis of their role alone runs counter to the lived experience of many people with disabilities and their families. Such exclusion by definition denies the fact that some service workers do transcend their roles.

necessary contribution, the urgency and clarity of political action can overshadow the slow and ambiguous work of building wider and deeper relationships with and around people with disabilities and their families.

Five trends that shape the strategy

At least five emerging trends make it urgent to mobilize political action and important to invest in the long term work of community engagement. Without both political action and community engagement, people with disabilities and their families will suffer a significant and unnecessary increase in the difficulties they face and communities will miss the kinds of relationships necessary to build a more just and more inclusive society.

Opposition to current policy and advocacy for individualized funding

Internationally, a growing number of concerned people and organizations note the inequities and costs of a system that keeps purchasing power in the hands of the human service system and control of the services people and families receive in the hands of service providers. They call for policies based on adequately resourced individual funding that puts people with disabilities and their families in charge of where, when, and how they receive assistance. They believe that this issue should shape political efforts to reform the way services are planned and provided.

For information on individualized funding and service brokerage

International

Individualized Funding Information resources
members.home.net/bsalisbury/

Canada

Family Alliance of Ontario
family-alliance.com

Individualized Funding Coalition
www.lefca.com/ifco

UK

Getting control of the money
www.buss.co.uk/via

US

Managed Care Clearinghouse Policy Briefs on participant-driven services
www.mcare.net/

State self-determination projects
www.self-determination.org/

Whether in Canada, in the United Kingdom, or in the United States a growing number of people with disabilities and families and their allies respond proactively to the threats of mechanistic cost cutting or cost management by working to reform systems in ways that increase the responsibility and discretion of service recipients.. Whether these efforts are called individualized funding, participant-driven supports, or self-determination they share a common rationale. Each approach to individualized funding implies a set of auxiliary mechanisms to assure well-informed decisions about budgeting, selecting services, and managing payments. This range of auxiliary innovations goes by various names: service brokers, personal agents, fiscal intermediaries, and vouchering mechanisms.

Desire to change faulty assumptions and the backward policies that result

Current policies continue an unfortunate pattern of under-investment in services to support people with disabilities. This results in growing numbers of people waiting for needed assistance, especially support to establish their own households, and many more people on the margin of having just enough assistance to survive. A continuing bias toward confining people with severe disabilities in institutions and nursing homes compounds the problem of

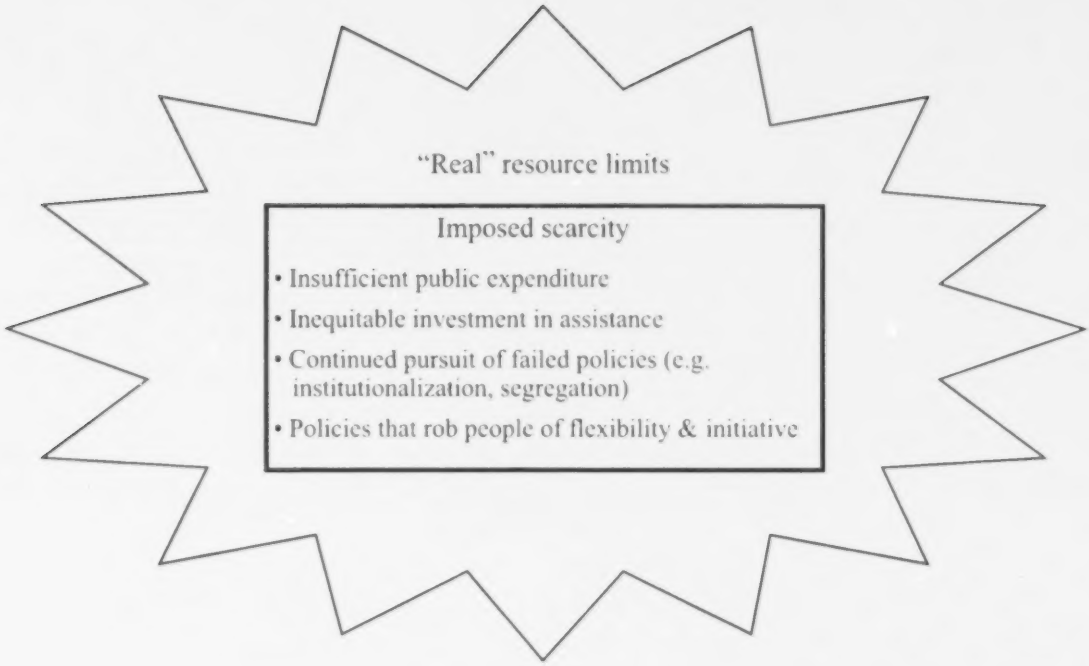
under-investment. People slip into nursing homes and sometimes into institutions when crisis overwhelms their family's ability to continue to provide assistance. Continuing investment in local services that segregate and control people with disabilities leaves many people unnecessarily isolated from community life. Arbitrary restrictions on the portability of funds trap some people and families in second-best arrangements. Allocation policies that most people experience as efforts to minimize government expenditure and restrict individual choice while imposing considerable uncertainty and stress on those who rely on publicly funded services further multiply the difficulties people with disabilities and their families are expected to assume.

This pattern itself runs deeper. It feeds on the enduring devaluation of people with disabilities, which remains all too common despite important achievements in enshrining the rights of people with disabilities in law. While political mobilization to defeat stingy and oppressive policies is necessary, it remains fundamentally important to work diligently to uproot prejudiced beliefs and discriminatory actions that are so commonplace that they remain invisible to many people whose behavior is controlled by them.

Competing understandings of scarcity

A widespread sense of scarcity drives under-investment in necessary assistance and justifies the bureaucratic cost controls that dominate so many people with disabilities and their families. Few people with disabilities and their families imagine limitless public resources, though control-seeking policy makers and their allies often accuse them of such fantasies. In thinking about issues of scarcity, it may be helpful to distinguish between "real" resource limits and scarcities imposed by policy.

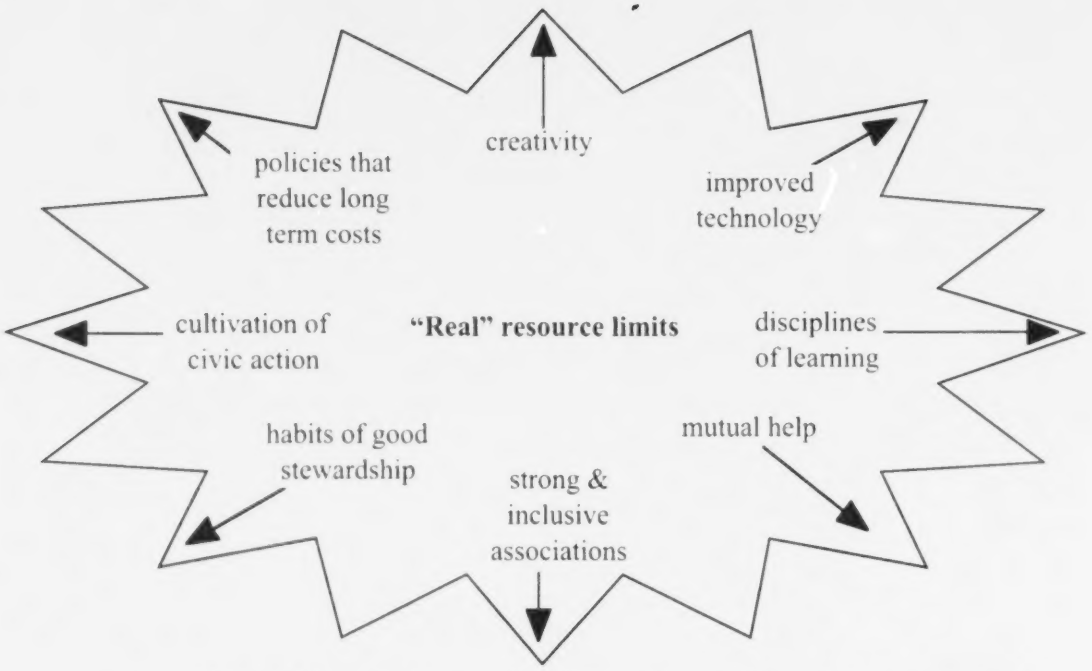
This diagram suggests the difference. The edge of the star represents such limits as the carrying capacity of the earth and the local economy given multiple legitimate demands on public funds and human energy. The edge of the box represents the scarcity created as a matter of public policy. The area between the edges of the box and the edges of the star represents the resources people can claim by working "outside the box".


"Real" resource limits
Imposed scarcity
• Insufficient public expenditure
• Inequitable investment in assistance
• Continued pursuit of failed policies (e.g. institutionalization, segregation)
• Policies that rob people of flexibility & initiative

Both political mobilization and community engagement can help people to notice the limits of the box created by policy and organize to systematically challenge them. Because the policies that impose scarcities serve important social and political interests –such as minimizing taxation or returning profit to nursing home investors or protecting the working conditions of facility based union members or reducing contact with socially devalued people– the box will fight strongly and skillfully to protect itself. Change comes through conflict with the powers the restrictions symbolized by the box serves.

Ongoing efforts to define the promise of adequate individualized funding as a means of dealing with real resource limits provides a foundation for raising consciousness and taking action to decrease imposed scarcity. The work of those people with disabilities and families who have made ways to minimize the bad effects of imposed scarcity on their lives provides inspiration and holds essential lessons to guide the design of processes for implementing a system of individualized funding that results in better lives for people.

Bracketing the *real* in "real" limits with quotation marks acknowledges the important reality suggested by this diagram: limits are *both* real *and* subject to purposeful efforts to push them back, such as the eight forms of action listed next to the arrows in the following diagram..



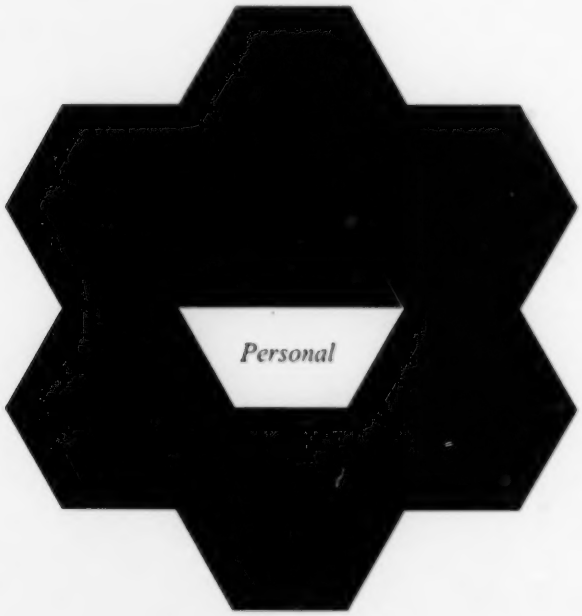
Most of these limit-expanding forms of action fall outside the power of policy makers to command. They lie within the power of groups of people with disabilities and their families and friends and co-workers and schoolmates and neighbors. Policies can create barriers or encourage these kinds of actions, but people must engage one another in making the most of what is actually available. Imaginative, responsibile people who have the benefit of strong mutual support and access to necessary knowledge, skills, materials, and funds have the best chance of producing better results in ways that push back the edges of "real" scarcity.

Knowledge of better ways

Practical experience, accumulated over more than 20 years by a growing number of people with disabilities and families around the world, demonstrates outcomes remarkably different from those commonly anticipated by people with typically low expectations of people with disabilities and community members. Given adequate support and assistance, people with disabilities create life circumstances deeply meaningful to themselves and their families and friends and significant to other people who have the opportunity to encounter them as classmates, co-workers, or members of a common effort. Under conditions of adequate support and assistance, people with disabilities know themselves, and come to be known by others, as possessed of gifts and responsible to make a real contribution to other's well being. With adequate

support and assistance, people with disabilities become increasingly able to communicate the direction their life should take, make good choices and develop the resiliency to recover from poor choices. Given the opportunity, people with disabilities find ways to challenge prejudice and discrimination that change the assumptions of those who meet them with open-able hearts and minds.

The conditions of adequate support and assistance can now be described with sufficient clarity to offer a clear standard against which to measure current practice and proposed changes.



The diagram above names the six building blocks that interlock to form a foundation on which people with disabilities and their families can strive to build a life that offers real opportunities for security, dignity, and contribution.

- **Personal support** means that a person with a disability knows that other people are at and on his or her side…

  …consciously and thoughtfully sharing life's experiences through time

  …encouraging opportunities for the development and expression of unique gifts

...joining creatively in figuring out what forms of assistance work best under changing life circumstances

...offering practical help

...gathering with others who care for pleasure or to meet the requirements of some necessity

...clearly confronting and challenging threats to well-being whether those threats come from the social and service system, other people, or even the person him or herself

...announcing, through lived experience, the benefits of living in mutual support. Personal support may come from parents, brothers and sisters, extended family, friends, or personally interested others

- **Person-centered planning** means that a person with a disability knows that other people are concerned to know, understand, and take direction from him or her in the ways they use whatever resources they can make available to the person. These resources may be shared time, or skills, or technology, or paid assistance, or funds. It suggests a systematic process for making, implementing, checking, and revising plans and ways of understanding the person's identity, gifts, impairments, challenges, and preferences.*

- **Responsive and flexible individual assistance** means that a person with a disability experiences a combination of personal assistance services, assistive technology, professional skills, and management (including, for example, needed help in designing a personal support system, recruiting, hiring, training, employing, scheduling, accounting for and supervising assistants) which...

  ...enables her or his participation in community life and respects her or his personal dignity and contributions

  ...adapts to the person's changing requirements through a process of negotiation and re-negotiation

- **Individual funding** means that ...

  ...an eligible person with a disability has adequate public funding to pay a fair price for necessary assistance

  ...the terms of receiving funding do not restrict his or her ability –or the ability of his or her family and friends– to negotiate when, where, and how necessary assistance is provided

* See John O'Brien & Connie Lyle O'Brien (1998) *A little book about person centered planning.* Toronto, ON: Inclusion Press. inclusion.com

…the process by which people establish eligibility and receive funding minimizes costs to the person and his or her family in terms of time, effort, intrusiveness and stigma.

- **Transition of existing services** involves a disciplined process of organizational learning, which continually improves the deployment of staff talents and skills and service system money. The most urgent transition involves recycling the resources now sunk in services which congregate and control people by design. Re-investing this time, talent, and money in the provision of flexible and individually responsive assistance frees new energy for individualized responses to people and families with individual budgets.. This involves moving from block funding to individual funding, carefully re-negotiating the expectations of people with disabilities and their families and friends, staff, and other citizens; liquidating investments in buildings with no future role in offering flexible and responsive individual assistance; and re-defining organizational mission, structure, and culture. Services that aspire to be personalized have a continuing obligation to improve their ability to make the best use of all available resources.
- **Community development** involves systematic effort to…

  …increase the number of community members who are directly engaged in good relationships with people with disabilities in such roles as classmates, neighbors, co-workers, association members, and friends

  …to assist people to organize and maintain support circles, family groups, assistance cooperatives, and other associations aimed at offering personal support and helping people effectively manage their personal assistance systems

A deeper understanding of the change process

For more than forty years, organized parent groups have worked with considerable success to reform services to people with developmental disabilities. Reflection on that history shows that changes in law and policy and expenditures are necessary but not sufficient conditions for extending the numbers of people with disabilities who build on the six foundation stones defined above. Service organizations can absorb new language and new techniques without much impact in the day-to-day experience of the people who rely on them. Government can adopt new styles for funding and regulating services without much impact of the day-to-day experience of the people who rely on them. Community members can remain separated from the lives and contributions of people with disabilities, simply assuming that the government and service workers adequately "take care of people like that." Without deep change in

relationships, assumptions and beliefs, and structures –without shaping a different culture– reforms fall short of their promise.

While it may be daunting to imagine working for this threefold culture change, anything less than working toward this change leaves people with disabilities and their families without the stable foundation necessary for a good life. Two considerations shape this work:

- Working to change culture is itself an important contribution that people with disabilities and their families and friends can make to the common good.* They must seriously consider accepting responsibility for overcoming the fears and barriers imposed by currently unresponsive cultures and assuming a central part in changing those cultures. Vulnerability neither excludes nor excuses people with disabilities and their families from the possibility of sharing actively in creating new relationships, influencing new mindsets, and shaping new structures. It would be a great mistake, founded in paternalism, to imagine that other's have to get the world ready before people with disabilities can participate in it.
- Despite faddish management book claims, quick and easy ways to change culture can't be found. Culture changes as adaptations and innovations accumulate in relationships, beliefs, and structures. The medium of culture change is day-to-day life. Solving the problems of supporting people with disabilities to make real contributions as cultural, political, and economic actors works the necessary changes. Images of working cultural soil to allow deeper roots for developing more complex and interesting and powerful relationships and images of bees carrying pollen from growing tree to

*For a powerful statement of this possibility and its responsibilities, read Jean Vanier (1998). *Becoming Human*. Toronto, ON: House of Anansi Press.

growing tree capture this work much better than images of industrial strength training events or media campaigns do.*

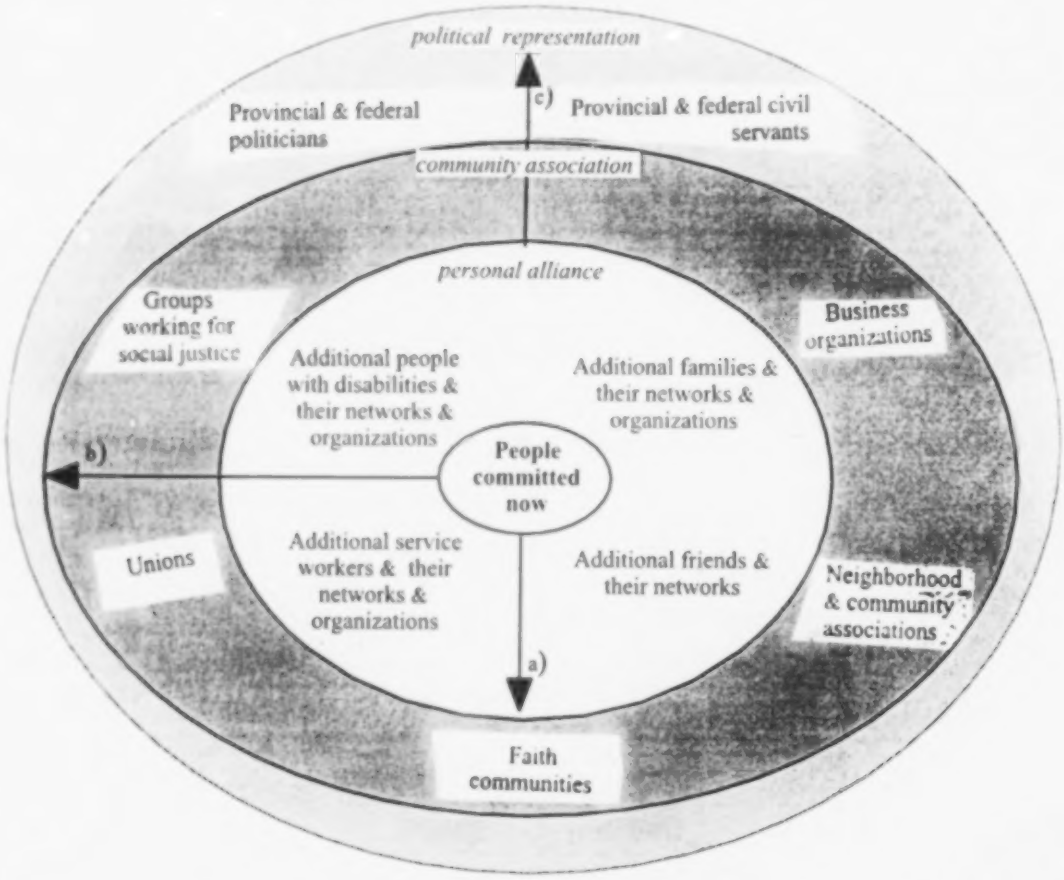
Two models of the community engagement process

Organizing relationships

The community engagement strategy will emerge as people now committed take actions that will result in…

…the direct, thoughtful **involvement of more people and associations** in the lives of people with disabilities and their families

…**higher levels of organization** among people with disabilities and their families and friends; this is signified by increasing numbers of people who sustain membership in family groups, support circles, citizen advocacy relationships, social advocacy campaigns, and other similar structures for mutual support and action



*See David B. Schwartz (1997). *Who cares? Rediscovering community*. Boulder, CO: Westview Press

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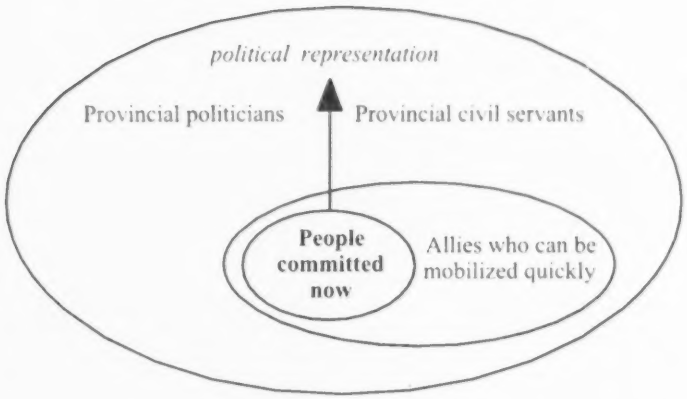
The diagram above suggests one way to look at this strategy. Committed people take purposeful action. a) They gather, organize, and support additional people to form sustained personal alliances (e.g. family groups). b) They assist people with disabilities, with the support of personal allies, to take up positive and active roles as contributing members of their communities' association life and economic activity. c) They encourage people, with the active support of personal allies and the community associations to which they contribute, to influence local, provincial, and federal politicians and civil servants to invest in funding the assistance they require to participate in community life.

This process of organizing mutually supportive personal alliances to enable the participation of people with disabilities in community associations calls for learning by taking action in the public sphere. Necessary action seeks creative accommodation from employers and association leaders. Necessary action demands the development of new and more responsive forms of personal assistance. Necessary action gathers people who will listen deeply and thoughtfully for people's capacities and gifts. This process of learning shapes the culture of service organizations more rapidly and the culture of communities more slowly.

The process makes significant demands on people with disabilities and their families. Experience shows that inviting them into community engagement is best done through what currently committed people call "kitchen table conversations." Such conversations allow people and family members to explore fundamentally important questions and to find their own voice with listeners they trust enough to share their kitchen table. Cultivating such relationships, and bringing people and families into personal alliances, is a deliberate art whose practice is paced by the people and families involved.

In contrast, the strategy for political action calls for quicker responses , as suggested in the following diagram. Political action tactics need a timely and direct impact on a carefully targeted issue. For example, political action is necessary to lay the single building block of individualized funding as a counter to a government controlled service assignment process. Coalition is fundamental to influence, and any shared interest will do to extend a coalition. Coalition members may not agree with or even know one another's whole agenda. Competition from other powerful interests usually leads to compromise and incremental movement.

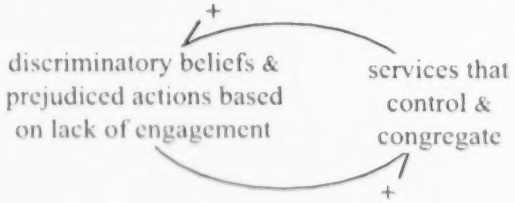


The two strategies complement one another. Political victory will provide more resources or more flexible resources to offer assistance to those working for community engagement. Even short of victory, political action offers an essential forum for people with disabilities and their families to assert their reality and avoid the temptation to behave passively as victims of the system. Success in community engagement will increase the number of people and groups who can be mobilized quickly when political action is necessary.

Shifting the circuits of culture

One way to explore a strategy for changing a complex situation is to imagine the smallest possible number of factors whose relationships could explain both the current situation and the shift from current reality to a more desirable state of affairs*

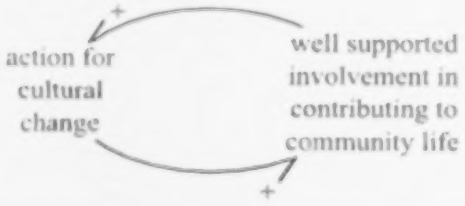
Much of our current reality could be understood as the effect of a mutually reinforcing relationship between two social processes. The (often unthinking) prejudiced behavior which flows from discriminatory beliefs about the value and possibilities of people which arise from a widespread lack of personal engagement with people with disabilities reinforces the existence of publicly funded and sanctioned services that professionally control and segregate people with disabilities. Segregating and controlling services reinforce discrimination and prejudice. The diagram below traces this culturally common circuit:



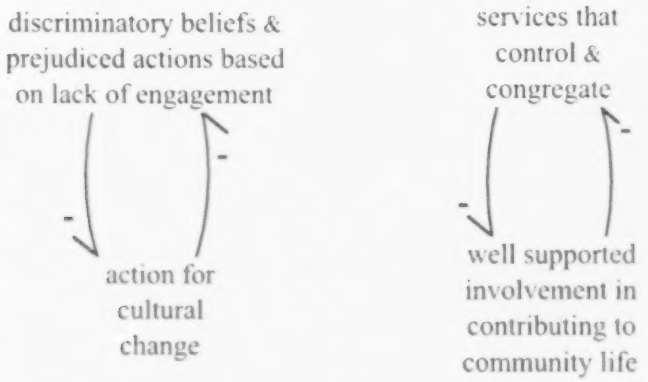
* This is a much simplified, amateur application of a set of tools for understanding complex systems described in Peter Senge (1990). *The fifth discipline*. NY: Doubleday.

Read the "+"signs to indicate that as one social process changes, the other changes in the same direction over time. That is, the more strongly people hold discriminatory beliefs, the more services that segregate and control people with disabilities there will be. And, the more controlling and segregating services there are, the more people will persist in their discriminatory beliefs. This loop controls most of the investments in the current system and it is worth looking for ways to weaken it even though it is very powerful. The "+"also argues that as services decrease the segregation and control of people, over time, discriminatory beliefs and prejudiced behavior will decrease in turn. Such change follows a rule of compounding: small changes in direction grow bigger with time. Remember that these diagrams don't claim certainty. They simply put a mental picture of how a situation could change out where others can see it and comment on it.

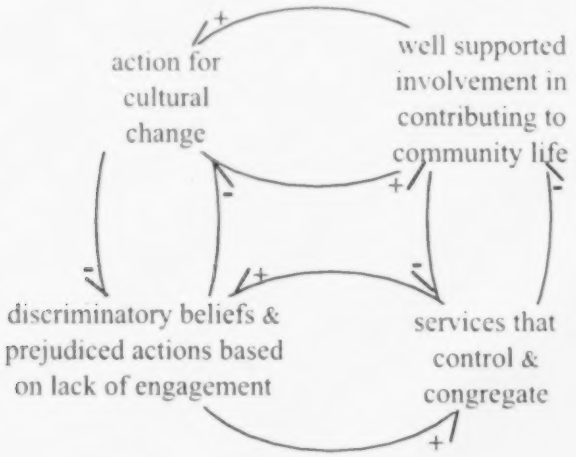
Segregation and control are not all there is. There is another loop that shapes culture by relating the day-to-day participation of people with disabilities who benefit from good support to contribute to community life and thoughtful action to change the culture. This is also a self-reinforcing circuit: as well supported involvement increases, so does action for cultural change; as action for cultural change increases so does the presence of well supported contributors. This loop currently controls only a small proportion of the talent, time, and money invested in the system. It's worth looking for ways to strengthen this circuit.



The social processes at the ends of each loop also influence each other, but in an opposite fashion. Read the "–" in the diagram below to indicate that as one changes, the other changes in the opposite direction: as action for cultural change increases, over time, discriminatory beliefs decrease. As control of people decreases (perhaps through the adoption of individual funding), over time, well-supported involvement increases.



Because our current reality has lots more discrimination and prejudice than action for cultural change, the initial effect of an increase of action for cultural change is likely to be small even if it is in a desirable direction. This reminds us that it can take a long time for small positive steps to make a societal difference that is easy to see. We can use this idea to notice that the community engagement strategy represents a sort of a bet. Those who invest in strengthening the loop that is currently much weaker are betting their energy and talent on a possibility. They bet that, over time, increases in the level of well supported involvement and action for cultural change will be amplified in ways that will begin to shift the culture. It is easier to imagine this happening within the culture of a service organization or in a segment of a community than in society at large. But the bet remains that a growing number of people supporting one another to take actions that change culture will reach a mass critical to making a large-scale difference. The diagram below suggests the way the two circuits dance with each other through time.



Those who have noticed that this diagram is too simple are ready to use the diagram as a tool to further develop a strategy for community engagement. As it stands, it packs more than one thing under each name. And the relationships asserted here depend on still other factors, such as the level of organization among people with disabilities and their families or the flow of information about what is possible and how things can be done. The next steps are to make the picture richer by identifying actions that will effect the social processes summarized here and then to try and test their effects.

The possibilities for action outlined below exemplify the process. They were generated by the Community Engagement Working Group in the context of making a change in Ontario's communities.

Possibilities for action

Create more family groups

Family groups have proven themselves a powerful vehicle for mutual support and creative social change. It has also proven difficult to seed new family groups in other areas.

- Find ways to help people who could facilitate the emergence of family groups to learn and practice the art. Perhaps a focused gathering, like the summer institutes sponsored by Inclusion Press, would increase the numbers of people strengthened by participation in a family group.
- Keep focus on the "family" in family groups. Family groups are not simply parent groups, they can include people with disabilities, their brothers and sisters, extended family members, and people who extend the family through a chosen relationship.
- Challenge family groups to discover more self-sustaining ways creating the assistance that people need. This will reduce the power the service system has over people by decreasing their reliance on its money. This approach could involve political action to modify the taxation and pension system to allow for people with disabilities to create and hold onto wealth. It could involve ways to further develop mutually supportive relationships.

Support leadership from among people with disabilities

While many people with disabilities will make their essential contribution to culture change by the way they go about living their relationships in everyday life, some people with disabilities have a call to exercise more public leadership.

- Involve People First in the community engagement process both organizationally and through its members.

- Challenge one another to notice and support leadership, especially among people who use non-typical means of communication.
- Find more ways that people with disabilities themselves can chose to make their network of relationships more intentional and more visible. The point is to disclose what is too often invisible: the real networks of relationships people with disabilities participate in creating.

Tell more powerful stories

The stories of people's real lives are our most powerful organizing tool. Reflection on the lessons of the stories of what people have achieved, where people get stuck, and how people deal with barriers is our most powerful source of learning about how to make changes. Our stories will be powerful if we focus on becoming better story-tellers and better learners from stories. We can...

...provide a "storytelling assistant" to people who need or want one

...encourage the use of multiple media: video, audio tape, cd-rom, drama, performance art, poetry, drawing, painting, sculpture, music as well as written materials and traditional testimony

...gather interested people to learn to tell their stories more purposefully by consciously choosing what and how to tell in terms of the needs of a particular situation

...call forth stories from different perspectives including the perspective of involved people with disabilities, the perspective of mothers and fathers, the perspective of brothers and sisters, the perspective of the people who provide support and the people who manage support organizations, and the perspective of engaged community members.

... gather people to exchange stories around a particular theme, for example the experience of dealing with bureaucratic barriers or the deeper meaning of the suffering imposed on people with disabilities and their families by the facts of social injustice

...create safe places for us to tell more of our stories, truthfully accounting for our own failings and fallibilities and errors and defeats as well as accomplishments and ways others place barriers in the ways

...create safe and effective ways to reflect on the lessons in our stories.

...gather people to discuss such dilemmas in storytelling as how to balance privacy with being able to define ourselves as we want to be known or how to deal honestly with the desire to tell an encouraging story in which straightforward steps lead to a desirable goal and the need to communicate the complexity and the "downs" as well as the "ups" in people's real situations

...find ways to tell and learn from "organizational stories" which describe how agencies and organizations design and adapt to the work of supporting community engagement.

Work sponsored by the J.W. McConnell Family Foundation suggests that listening to stories from community leaders may be a powerful tool for working in the circle of community association.*

Keep person-centered planning vital outside the orbit of the service system

Person-centered planning provides a variety of helpful ways for people with disabilities and their families and friends to consider critical questions about desirable futures and to guide action. As the service system adopts some of its techniques and language, it is important to encourage people with disabilities and their families to maintain the capacity to plan independently of the service system.

- Offer interested family members and friends and people with disabilities training and support in facilitating person-centered plans.
- Match more experienced families with less experienced families as mentors in the process.

Develop more ways to gather and disseminate information

Being in contact diminishes the loneliness that discourages people from finding their voice and taking action. Information about what others have done and how they have done it communicates a sense of possibility and a challenge to organize to take action.

- Convene a gathering of family groups and support circles at least annually.
- Develop clear and straightforward guides for family members that describe what experienced others have learned about such things as recruiting and managing personal assistants, finding or developing suitable housing, settling on a workable individual budget, making the best use of available benefits, etc.
- Continue to develop web pages as a source of contact and information.

*See V. Cammack, et al. *Report on the feasibility study of creating enabling community initiatives*. agora.qc.ca/v5n2.html

Maintain clear links to political action while pursuing a distinct strategy

It is as important to build strong connections between the people involved in political action and those who meet through community engagement initiatives as it is to keep energy focused on the long term strategies for community engagement.

- Current efforts to engage 50 new Toronto families in making good plans with help from experienced family mentors and then collectively specifying the exact system barriers to their realization to responsible Ministers and to their own legislative representatives seem promising and could be repeated in other places.
- Members of support circles or family groups or any other personal alliance should encourage one another to stay politically informed and active. Having specific members take responsibility for overlapping membership with political action campaigns would strengthen both efforts.

Develop cooperative projects

Several organizations have interest and experience in community engagement strategies; it is worth exploring ways to cooperate in seeking funding and carrying out projects.

Offer formal learning opportunities

Many leaders in current efforts have benefited significantly from participation in courses on social role valorization and person-centered planning.

- Assure that such events are available and accessible for people to attend.
- Find ways to develop new events based on what participants in the community engagement strategy have to teach.
- Carefully consider the way in which people with disabilities will have a teaching role in these events.